Child and Youth Long Term Services
Guidelines

Health and Welfare Canada
Santé et Bien-être social Canada
Canada

88-01878/

REPORT OF THE SUB-COMMITTEE
ON INSTITUTIONAL PROGRAM GUIDELINES

GUIDELINES FOR ESTABLISHING STANDARDS

CHILD AND YOUTH LONG TERM SERVICES

Health Services Directorate
Health Services and Promotion Branch

Published by the authority of the
Minister of National Health and Welfare
1985

Également disponible en français sous le titre
"Services prolongés pour enfants et adolescents"

I M P O R T A N T

The information contained in these guidelines was current at the time of publication. When using the guidelines it should be remembered that certain aspects of the delivery of health care and health technology are changing rapidly. Should you identify any out-of-date material in the text, please inform:

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Cat. No. H39-42/1986E
ISBN 0-662-14584-4

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GENERAL INTRODUCTION

Background

Advances in health technology and changes in the planning and delivery of health care have contributed to an increasing demand for specialized care facilities and services in institutions. A dramatic rise in the number of intensive and specialized care facilities and services in hospitals has occurred in recent decades due to rapid technological development in electronics and automation, and as a result of new approaches to patient care. These changes have produced demands for physical facilities, specialized equipment and highly-trained health manpower. In addition, health care professionals are increasingly emphasizing the need for continuum of care from prevention of illness to chronic care in the community with admission for institutional care being a potential part of this continuum. Identification of required service linkages is therefore necessary.

Consequently, there is a continuing need for guidelines for standards to assist those involved in planning, organizing and operating institutional programs and services.

Mandate

In 1972, health authorities in Canada recognized the need for guidance in this area and the Federal-Provincial Advisory Committee on Health Insurance commissioned the Working Group on Special Services in Hospitals to create guidelines for standards to provide a reliable definition of requirements for a number of special care facilities and services.

Guidelines were developed by the Working Group for 14 units and services, and, in 1975, these were published under the title, "Guidelines for Special Care Units in Hospitals". This volume was widely

distributed to provincial health and hospital authorities, and to national and international health organizations, and has been adopted by many as a guide.

The continuing development of existing and new health technologies, together with changes occurring in the pattern of health care delivery, gave impetus to the updating of the 1975 guidelines, and to the development of guidelines in additional areas. In May 1982, the Federal-Provincial Advisory Committee on Institutional and Medical Services granted the Working Group continuing status as a sub-committee of the Advisory Committee, called the Sub-Committee on Special Services in Hospitals. With the continued broadening of the scope of the work, in 1985 the name was again changed to the Sub-Committee on Institutional Program Guidelines. A complete list of guidelines published or being prepared by the Sub-Committee is appended.

Methodology

The guidelines published in 1975 were developed on the principle of a consensus of information, knowledge, experience and expert opinion obtained from appropriate organizations and individuals throughout Canada. They were based, where possible, on guidelines developed in Canada, and from authoritative sources in other countries. This approach has been generally acceptable to government and hospital authorities and the health professions.

The present guidelines were prepared on a similar basis. On this occasion, in addition to input from provincial authorities, the expert opinion of health professionals was obtained through formally designated representatives of national health organizations representing the activities involved in each specific service. It is certain that many hundreds of health professionals from every area of

the country have provided expert input in these guidelines by this method, and have thus provided a truly Canadian consensus on these topics.

Suggested purpose of the Guidelines

The guidelines should not be regarded as rigid standards. Their application may vary throughout Canada, and it is the prerogative of each province to accept, modify or reject the guidelines according to provincial priorities.

The purpose of the guidelines is to provide a definition of requirements for a number of institutional facilities and services. They are not intended to provide standards for clinical practice.

Where development of a unit/program is under consideration, the guidelines will assist planners and government health authorities in determining the need for such a unit/program, and in assessing the total potential impact of a new unit/program on existing and projected services, both at the local and regional levels. Deficiencies in existing services can be identified, and in some cases these can be corrected without the need to develop a new unit/program.

Where a unit/program already exists in a facility, the guidelines will help to identify problem areas related to administration, personnel, equipment, and physical facilities. They will help to determine necessary remedial action and to set priorities for corrective measures on the basis of clinical need, fiscal realities, and the degree to which a deficiency in the physical facilities impedes adequate functioning of the unit/program.

Future revisions

Because of the rapidly changing nature of health care, the guidelines will require regular revision. The Sub-Committee will plan and oversee revision of the guidelines.

Acknowledgements

The Sub-Committee acknowledges with sincere appreciation, the immense amount of work undertaken and time given by practising health professionals in Canada, in providing detailed written information and guidance in the preparation of these guidelines. In addition, we wish to thank the many others who, in any way contributed advice and information to this endeavour.

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GLOSSARY

Child and Youth - For the purposes of this document the period addressed is from birth to 18 years (or the upper age limit defined in each province)

Disability* - Disability is the loss or reduction of functional ability and activity that is consequent upon impairment. (It is characterized by excesses and deficiencies of behaviour and other functions customarily expected of the body or its parts. It involves functional limitation and/or activity restriction.

Family - Members of a household, parents, children etc; sets of parents and children, or of relatives, living together or not.

Friend - A person who is attached to another by affection or esteem and mutual benevolence independently of sexual or family love.

Guardian - The legally recognized relationship between a specified competent adult and a dependent child/youth. The capacity is vested in the guardian to be exercised in the best interests of the dependent child.

* As defined in International Classification of Impairments, Disabilities and Handicaps. A manual of classification relating to the consequences of disease. World Health Organization, Geneva, 1980.

Handicap* - Handicap is the disadvantage that is consequent upon impairment and disability. (It represents the social and environmental consequence to the individual stemming from the presence of impairments and disability).

Home - The social unit formed by a family living together. Includes different types of families such as foster care and youth congregate living.

Impairment* - Impairment is a generic term that embraces any disturbance of or interference with the normal structure and functioning of the body, including the systems of mental function. (It is characterized by a permanent or transitory psychological, physiological, or anatomical loss or abnormality, and includes the existence or occurrence of an abnormality, defect, or loss in a limb, organ, tissue, or other structure of the body, or in a functional system or mechanism of the body).

Main Caregiver - The person in the child's or youth's life who provides most of the child rearing and health care; has done so for long periods and will probably do so in the future. Usually, but not necessarily, a parent.

Parent - The biological or adoptive parent.

Referral Centre - A centre of expertise giving specialist advice on assessment and treatment of children and adolescents who (may) require long term care. Depending on the nature of the care required and the availability of such services a "centre" may range from a single specialist to a fully equipped and staffed regional assessment and treatment centre.

Respite Care - Short term care given to the child by appropriate professional services with the sole purpose of providing temporary relief to the main caregiver.

Supported Independent Living - Accessibility, including funding of services determined by the person to enable him/her to live as independently as possible in a residence type of his/her choice.

CHILD AND YOUTH LONG TERM SERVICES

I PLANNING AND ORGANIZATION OF CARE

PREAMBLE

Most Canadian children today enjoy good health and unimpeded development. However, for some children and youth, impairments in physical, psychological, social or intellectual development lead to long-term contact with systems providing specialized medical, educational or social care beyond usual requirements of normal development. These children and their families may enter into extended contact with systems on which they must rely for help, support, advice, treatment, relief and counsel. Because the nature, quality and impact of these systems vary, they can create tension and anxiety in the clients, whose range of disabilities can at the same time induce feelings of impotence and frustration in the care-givers.

The purpose of the guidelines is to outline a system of care for children and youth who require long term care.

"Long term care" is often considered to be synonymous with "institutional" care. For the purposes of these guidelines, an institution is "... an organization, establishment, foundation, society or the like, devoted to the promotion of a particular object, especially one of a public, educational or charitable character". The tangible element of institutions in this context will therefore be the organized programs they provide - medical, psychiatric, rehabilitative, custodial[1], rather than "the buildings devoted to

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[1] For example, juvenile detention centres, reform schools.

such works". These guidelines therefore stress the programmatic elements of long term care, in the context of the following assumptions.

1. BACKGROUND ASSUMPTIONS

1.1 The Child as a Person

For children and youth needing long term care, service systems tend to focus on the medical, social and organizational dimensions of care. This makes it easy to ignore the child as a person with unique qualities and needs. All children must grow, develop and change throughout their dynamic formative years, even when biological or psychosocial forces limit or distort those processes. Children and youth in long term care must especially be accorded the opportunities for full self-realization.

Leading theorists on child development emphasize the importance of psychosocial stages of self-realization, of intellectual development, and of the transactions between child and care givers throughout the developing years. Evidence has been developed to support a non-categorical (non-diagnostic) approach to the needs of the chronically disabled and their families, and it has been shown that special children are more like other children than they are unlike them. However, children who grow up with a chronic disadvantage have special developmental needs.

When children's biomedical, psychosocial or developmental differences draw them into continuing long-term care, it is easy to emphasize the problem rather than the person, and to fail to see the ordinary elements of childhood that still exist. A restrictive medical perspective on chronic biopsychosocial disadvantage may compound this tendency to overlook normal personal attributes. For instance, a child requiring a certain amount of help with an activity of daily living should get such help from caregivers. However, it is often easier and faster for the adult caregiver to complete the total activity

themselves rather than to encourage the disabled child's active participation. This may stifle the potential for self-worth through accomplishment, autonomy and control. In ordinary circumstances, a constantly growing sense of independence is expected as a consequence of exploration, risk-taking, experimentation and feedback from one's efforts. In these exceptional situations, opportunities for growth can easily be lost, at a cost to the child's overall development of competence and ego fulfillment.

Erikson's formulation of the psychosocial tasks of development (see Table I) are correlated with the implications for care and services as provided by community facilities. It should be clear that the implications of a broad perspective on childhood and family development will impose many important demands on the services created to care for children and families in need of long term care.

Facilities and programs for children and youths with special needs (and their families) must be flexible enough in their location, content and approach to respond to the continuously changing and evolving individuals for whom the services are provided, and must give equal value to the psychosocial as well as the medical needs of the children.

To the greatest extent possible, those children and their families should be involved in delineating the programs of care, in partnership with professionals.

1.2 The Child as Citizen

While children are traditionally considered to "belong" to their parents, the Canadian Charter of Rights entitles children to the same rights, freedoms and priviliges as adult citizens. This includes being afforded the same dignity, respect and access to community resources.

For children whose medical or developmental status requires extraordinary caregiving by adults, these rights may be particularly vulnerable. They should

TABLE I: ERIKSON'S STAGES OF PERSONAL DEVELOPMENT: IMPLICATIONS FOR ORGANIZATION AND PROVISION OF SERVICES

Age	Task	Correlates in care & services	Services
Infant	Trust	Continuity of parenting. Environment which provides sensory stimulation and opportunities for movement and play.	Home Care, care by parent units, open visiting. Ambulatory services, parent counselling, play programs in hospital.
Toddler	Autonomy	Opportunity for development of individuality with minimal restriction; exploration, experience appropriate to age and stage, whatever the health problems.	Home Care, day hospital programs, ambulatory services, parent counselling.
Pre-school	Initiative	Opportunity to establish social relationships, cope with peer competition and to establish some independence from parents and care-givers.	Home Care, day programs, pre-school programs, ambulatory services, parent counselling.
School age	Industry	Opportunity to learn, to attend school, to develop responsibility and work habits and to acquire a sense of competence.	School programs, either through integration or in special programs, recreational/creative arts programs, ambulatory services, parent counselling.
Adolescent	Identity	Opportunity to develop a sense of self as a separate independent person with appropriate self-sufficiency. Opportunity to explore peer relationships, to separate from family and to assume complete responsibility for self-care. Opportunity to acquire a sense of ownership of own health problem, and to view self as an emerging adult, about to enter the adult work.	Peer contact programs, recreation/creative arts programs, sexuality/health education programs, work training programs.
Young adult	Intimacy	Opportunity to explore intimate relationships with both sexes, to explore own life style options, and to assume independent living to maximum extent possible.	Alternative to home, work opportunities, social opportunities.
Mature adult	Generativity	Opportunity to gain sense of being productive contributing person, to explore own creative potential and to have satisfying relationships with others.	Parental participation in and control over planning, implementing, and evaluating programs for "special children and families".
Elderly	Integrity	Opportunity to view life as one over which person has had reasonable control and autonomy and can therefore assume responsibility for how life has gone.	

1. Erikson, E.H., Childhood and Society, 2nd edition, 1963 New York, Norton, p. 90

be encouraged to participate in decisions about their own care after being appropriately informed. Children should also enjoy the right to be informed of their medical status and options for treatment. They must therefore at all times be considered the backdrop against which decisions about care, treatment and management are made.

1.3 Social Trends

There is a noticeable shift toward mainstreaming of the disabled and retarded into society. Chronic care institutions are being closed, and patients moved into smaller community facilities and to their parents' home. Consumerism is leading to a better informed and more demanding public. Parents are more ready to play an active role in caring for children with chronic mental, developmental or medical disabilities.

At the same time, the percentage of single parent families is rising steadily and family mobility often leaves parents far removed from extended family support in times of stress. Unsettled economic conditions mean that more mothers must work to help support their families. And since there is a documented relationship between many forms of psychosocial morbidity and lower socioeconomic status, such status may increase the burden on many families with a child requiring long term care.

2. EPIDEMIOLOGY

Estimates of the prevalence of severe chronic illness in children under 16 range from 1 to 1.5 per cent of the child population but that estimate may be broadened to 10 per cent, to include the complete range of chronic problems affecting physical health. Of these children, only 2-3 per cent are thought to experience problems causing limitation in the normal range of daily activities. (In this context a chronic health condition is taken to mean one lasting more than three months, or requiring a period of hospitalization of one month or longer.) Several epidemiological studies in North America, Scandanavia

and the British Isles show that the prevalence of severe mental subnormality (IQ less than 50), which usually includes children with multiple congenital or severe neuromotor disabilities, is approximately 3.5 to 3.8 per thousand, usually referring to the age range 5-14 years.

There are 7.8 million children between 0-19 years in Canada (1981 census). Using prevalence estimates from epidemiological studies in comparable populations, it is conservatively expected that 780 000 (10 per cent) children and youth in Canada have some form of chronic illness. Of these 195 000 (2-3 per cent) can be considered functionally limited. Approximately 27 300 (3.5 per thousand) are likely to be severely mentally handicapped. The extent of primary psychosocial dysfunction is unknown, but estimates from epidemiological surveys, extrapolated to Canadian populations, suggest that approximately 12 per cent or 936 000 Canadian children show some evidence of clinical maladjustment.

3. PRINCIPLES OF SERVICE DELIVERY

Philosophic Principles

1. The rights of children and parents are recognized to be of paramount importance in all service planning.

2. Continuity of the family's role and responsibility is recognized and supported both when the child is at home or in a residential setting.

3. Services must respond to developmental needs of the children to foster the most healthy development attainable for each individual.

4. The system should be organized to recognize that children are part of a total community and should, whenever possible, live and be served there. They will also need transition services for many will ultimately require care in equally good adult services.

5. The service should be responsive to cultural needs.

6. The system should have, and should regularly monitor, criteria for excellent service.

7. Access to the services must be available to all.

Organizational Principles

1. The services should be available to children and families with the full range of health and social disabilities, physical, intellectual emotional and behavioural.

2. This will require a spectrum of services which should include:

(a) a complete diagnostic assessment leading to a treatment plan. This should involve all necessary professional services since treatment may range from intensive to occasional outpatient therapy activities or be limited to intermittent contact services for the child who is living and functioning in the community. These services should include monitoring and health maintenance activities which are in part preventive;

(b) home and community support programs (educational, medical, social, recreational, spiritual, respite);

(c) partial care programs such as day programs;

(d) acute hospital care;

(e) total care services of residential and institutional settings.

3. The system should afford the individual maximum opportunity to function in the community as much as and for as long as possible, using all available resources and services.

4. The system should provide active advocacy to ensure properly funded good quality programs to integrate and normalize the individual's living.

5. Children and youths with long term disabilities should have someone within the system who integrates and coordinates the services that they require.

6. The system should provide active treatment and promote optimal function of each child in the least restrictive environment possible.

7. Emphasis should be on programs. Programs imply organized patterns of activity that are goal-directed and may be carried out at a variety of facility and community-based sites.

8. The breadth and complexity of services required by children with long-term disabilities usually means that all professionals who work with them require special training. The impracticality of having professionals from all disciplines interact with each child and family means that traditional professional roles and functions need to be extended and boundaries relaxed.

9. Services should include well-defined and financially supported programs of prevention to combat the higher rate of emotional disturbances experienced by this population. These programs should encompass care, education and guidance with continuous monitoring of the child's and family's progress and coping, and consideration of the child's peer relationships.

10. All agencies who deal with these children should welcome students and these students should be supervised by their instructors or experienced staff members. There should be enough flexibility between agencies and facilities to allow students to move with their young clients when

those children move or are transferred. Students from disciplines such as nursing, medicine, education, administration, social work and other professions are often assigned to work with these children or in these facilities and agencies. The type of learning that takes place when contact between student and child occurs over time (rather than in brief episodes) offers the best opportunity to understand the nature of care required by these children and families.

11. The transition from child and youth services to adult programs must be flexible and coordinated between programs. Where there are no special adult programs, children's programs should ensure that essential services are provided and development of appropriate adult programs supported.

12. Since a child is a member of a family, no matter where that child lives, programs should recognize and support family functions. The family and program staff must collaborate in planning and implementing care.

13. If care at home cannot be provided, programs should be available to maximize continued family contact. Residential care should be as home-like as possible.

14. Services should have effective staff support and training programs, with a commitment to continuing staff education.

15. Services should fulfill a role in public education, and in promoting a positive public image of the people they serve.

II SERVICE SYSTEM COMPONENTS

1. AWARENESS, ACCESSIBILITY AND SCREENING

Certain mechanisms can help to ensure that children requiring investigation are referred for appropriate diagnosis and management. These include:

1.1 Awareness

Identifying disorders and assessing the child with special needs requires recognition of symptoms and referral of the child for evaluation. This calls for not only a knowledge of signs and symptoms of the disorder, but also of the available assessment and treatment procedures and services. This knowledge should be promoted through the continuing education of primary care physicians, health care professionals and educators. Community and government agencies should disseminate information on special conditions to the public and give advice on where to go for help.

1.2 Accessibility

Where there is concern about a child's condition, specialist opinions and services should be sought. There is legitimate debate as to whether access to these services should be universally available. Unlimited access can undermine relationships between elements of the system and exhaust limited resources. However, frequently parents report that they encounter obstacles to obtaining full assessment and treatment for their children. An open door policy where a parent can go directly to a specialist provides some insurance against these problems.

Whether access is universal or restricted, special efforts must be made to identify those at risk of not being able to obtain the assessment and treatment services they require, and to ensure their access to the system.

1.3 Screening

Criteria

Screening programs are established to detect disorders or risk factors among apparently healthy people in the community. This may result in labelling people as diseased or at special risk months or years sooner than would routine symptomatic care. The benefits of early detection must be weighed against the consequences of such labelling.

Since we often lack the evidence to prove that early diagnosis and presymptomatic detection of a given condition improve prognosis[2], screening programs should be initiated only if:

- the effectiveness of the screening program has been demonstrated, preferably in a randomized trial;
- efficacious treatments are available and programs are accessible;
- the current burden of suffering warrants screening;
- screening tests are cost effective, acceptable, reliable and valid with good specificity and sensitivity;

When these criteria have not been met, case finding procedures should be carried out instead of routine screening.

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2 Canadian Task Force on the Periodic Health Examination, "Periodic (vs. annual) health examination," CMA Journal, Vol. 121 Nov. 3, 1979, pp. 1-45.

2. REFERRAL AND CONSULTATION

Referral and consultation are important elements in assessing and treating many children and youths who require long term care. Specialists who have intimate knowledge of the condition and of the resources for its treatment can usually identify the disease or disability. Referral can contribute greatly to the prevention of a secondary disability. Referral for assessment of complications arising during the treatment period can also help to prevent further disability.

2.1 Graded Referral

Opportunities should be available for a graded level of referral and consultation offering a variety of options for communications on patient problems. The referral centre should encourage informal contact. Options include:

- telephone consultation, including teleconference calls;

- closed circuit or committee television links;

- computer hookups for information exchange;

- full consultation with a treatment plan to be carried out locally;

- consultation, with treatment carried out locally but review by the consultant over an extended period of time;

- complete transfer of responsibility for assessment and management to the referral centre.

While referral may result from a decision by the local team leader, informal consultation should be open to all professionals.

2.2 Communication and Feedback

Human factors must be considered in the design of systems for referral and consultation. Cooperation and trust established between providers and institutions and between individuals within different institutions ensure that the different parts of the system work together in the best interests of the child and the family. This is reinforced by speedy communication back to the source of the referral. This communication can be used as an opportunity to encourage more sophisticated and appropriate referral.

2.3 Decentralization

Designing an effective system of referral and consultation requires the highest level of expertise and service with the smallest disruption of normal activities of families and patients. In human services it becomes increasingly difficult to deliver sensitive, flexible and humane care once the central institution becomes too large or its territory too great. Referral centres will work best when they come to know and to work with the personnel and resources within their referral area so that as much care as possible can be provided close to home. Consequently, indirect consultation, by providing advice or assistance to the community, should be encouraged.

2.4 Education

When referral centres start to serve a wider territory, they have a commitment to participate in continuing education. The referral centre should provide this education in the local setting.

2.5 Confidentiality

Availability of information obtained through the referral and consultation process is important in providing effective service to the patient and the family and maintaining of positive relationships

between service professionals and institutions. As the range of services expands, there is an increasing volume of detailed personal, social and psychological information. Because there is a growing concern about uncontrolled dissemination of such data, detailed reports in these areas should probably be separated from the body of factual information and be distributed selectively on a "need to know" basis. Provincial legislation regarding confidentiality issues must be recognized.

2.6 Information Sharing

The patient and the parent have the greatest need to understand the results of assessment. But there is often reluctance to share reports with them because evaluations of personality and lifestyles may appear judgmental. These judgments are frequently essential to decision-making but should be left out of the body of a report so that they can be communicated sensitively and discretely by the person who deals most directly with the client. This may allow the institution to give patients and parents a copy of the formal report for later study and reference pursuant to provincial legislation and institutional bylaws. Some authorities have suggested this be incorporated in a health record carried by the family and available at all health encounters.

3. DETAILED INTERDISCIPLINARY ASSESSMENT

Referral sets in motion an assessment process that is usually interdisciplinary. Its objective is to define the problems as follows:

- a detailed medical assessment and diagnosis including sensory, neuromotor and general physical status;

- estimation of developmental achievement and potential (including educational assessment);

- mental health evaluation;

- family assessment, including social history, coping style, opportunities for individual growth, and financial and practical ability to carry out the program; and

- environmental assessment including identifying the need for aids to daily living, environmental modification, mechanical devices and appliances, orthotic devices, communication programs, and transportation requirements.

Professionals providing input to the process may include:

physician, nurse, occupational therapist, recreational therapist, physiotherapist, audiologist, aural habilitationist or education of the hearing impaired, child life worker, educator, geneticist, social worker, speech and language therapist, psychologist, rehabilitation engineer, pharmacist, orthotist, dentist, nutritionist, vocational counsellor, chaplain, child care worker, teacher.

Intake procedures should priorize patients to be seen and identify and collect results of previous investigations, treatments and evaluations. This will allow preliminary vetting by the conference coordinator (see page 18) to select which evaluations may be relevant to the interdisciplinary assessment.

4. INDIVIDUAL CARE PLAN

The interdisciplinary assessment should lead to a case conference where the various assessments can contribute to the development of an individual care plan (ICP). The conference will usually occur at the centre where the child was seen but the opportunity to hold the conference in the patient's community should be considered. Other options designed to bring care close to the community include conference telephone calls involving local teachers, physicians, public health nurses, etc.

Wherever possible, the child or youth and the family (see also pages 35 to 41) should be included as part of the team.

The individual care plan should:

- Define current problems and level of function.

- Determine goals and objectives of treatment.

- Determine priorities and assign specific frequency and criteria for measuring progress. A goal-oriented record can facilitate this.

- Assign responsibilities to individual members of the therapeutic team.

- Define procedures for reviewing and modifying diagnoses, functional assessment and treament.

- Establish criteria for terminating treatment, or for discharge.

- Nominate one person who ensures that the ICP is carried out. (Depending on the complexity of management, this may be the patient, a family member, the personal physician or an assigned case manager).

- Identify community support, including respite care.

- Identify opportunities for social and recreational activities.

The plan should also promote independence and responsibility and should be as non-intrusive as possible. It should emphasize normalizing the individual and promoting community acceptance and interaction. It should be recorded in writing, and each member of the treatment team, including the patient and/or family, should have a copy. Relevant social, recreational, dietary and spiritual activities

should be included as part of the plan. In developing an educational plan, life skills development plays an important role.

The team should review the ICP when necessary at least annually for older children and more frequently for preschoolers. Each team member should be encouraged to refer concerns for team discussions in conjunction with the case manager and the conference coordinator and be able to request a full team review.

Support must be given to the family members. Staff should be aware that the family is often under stress and should watch for signs of cumulative strain i.e. strain that increases with additional problems or becomes increasingly heavy with the passage of time.

Conference Coordinator

With the number of participants involved in the assessment and formulation of the ICP, the role of the conference chairperson is critical. Unlike the case manager who is responsible for the patient, the conference coordinator is responsible for organizing team function. It is his or her responsibility to allocate the institution's resources and to see that professional tasks are carried out. This may include screening referrals for appropriate professional assessments, mandating contact among professionals and their community counterparts, marshalling reports for the ICP and chairing the case conference, setting dates for review and establishing the accountability of the case manager.

5. CASE MANAGEMENT

Case management means seeing that the patient receives all the services specified in the ICP through health care and related systems and that such services match defined needs. Case management may be a delegated role where the legal responsibility remains with the physician responsible for providing

health services. Case management enhances accountability and shows that the institution is responsible for the effect of the overall system. The case manager also serves as a personal link between the patient, the family and team members.[3]

The case manager should be known to all team members. In addition to monitoring the elements of the ICP, the case manager's duties include:

- Explaining the management plan to patient and family.
- Serving as the day-to-day link between patient and agency.
- Reporting any service delivery problems and changes in the patient's situation which would require changes in the case plan.[4]
- Ensuring availability of current case summary. A copy in the patient's possession facilitates contact with professionals and institutions.

Case management also benefits the service delivery system itself. By coordinating and evaluating services, treatment becomes more effective; unnecessary duplication of services is eliminated. Clearly defined accountability becomes an element of quality assurance for the health program.

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3 Intagliata, James, "Improving the Quality of Community Care for the Chronically Mentally Disabled: The Role of Case Management," Schizophrenia Bulletin, Vol. 8, No. 4, 1982, pp. 654-674.

4 Judge, Martin, "Supermarket of Services Allows Dependent Adults to Avoid Institutionalization," in Flyn, and Nitsch, eds., Normalization, Social Integration and Community Services, University Press, 1980, pp. 313-322.

6. CARE ADVOCACY

The extent to which advocacy is required will depend on the complexity of the patient's needs and the resistance of individual service components to meeting those needs. The case manager can often advocate directly on the patient's behalf to clarify needs and arrange for services.

Children who are under the care of provincial authorities and not their natural parents often move from one jurisdiction to another and this can interrupt medical and developmental care. Advocacy on behalf of these children and youth represents a particular challenge. This should be the responsibility of all those involved in the care and education of the individual, but one individual may be designated as "most responsible."

7. REGISTRIES

Registries foster enhanced service by providing a data base conforming to provincial legislation, for research and resource development as well as facilitating the evolution of community self-help groups. Patients and families can readily be given a listing of available services and quickly updated about applicable developments. However, these are costly undertakings whose usefulness diminish if they are not kept current and accurate. In certain jurisdictions a regional facility serving all cases of particular type could function effectively as a developer of the case registry.

8. DELIVERY OF SERVICES

The development of human rights and consumer movements has resulted in programs to equip disabled people to live independently in the community. With the support of appropriate services, many younger people with special needs can take responsibility for health care needs and make realistic choices for life management. Maintaining

the child or youth in the family home is advantageous to the child, the family and society in general. Parents may need education and therapeutic programs to help them support and encourage their children to be as independent as possible. Self-determination can also sometimes be achieved through foster homes or legal adoption.

The setting for the delivery of services will depend on the type of service required, the availability and portability of the service, the suitability of the home environment, the physical and emotional status of the child/youth and the capability of the family to support the programs.

8.1 Age-Appropriate Support Services for the Child at Home

Larger communities in Canada already have agencies that provide a range of home care services which can allow the child to remain in the home; these services are becoming increasingly available in smaller communities. Table II lists the commonly used services, but is not exhaustive. Some of the services listed may be offered as free-standing services or may be part of a home care service.

TABLE II COMMUNITY SUPPORT SERVICES FOR THE CHILD LIVING AT HOME

a. Acute non-emergency medical care
b. Ambulatory hospital services
c. Homemaking
d. Laboratory
e. Nursing
f. Medical supplies
g. Occupational therapy
h. Physiotherapy
i. Respiratory
j. Speech, language pathology and auditory therapy
k. Attendant care (assistance to parents in some aspects of care such as heavy lifting)
l. Child care
m. Education including techniques for the hearing impaired and the blind.
n. Rehabilitation engineering
o. Infant developmental programs
p. Home modifications
q. Mobility orientation workers for the blind
r. Nutritional counselling and support
s. Pastoral
t. Respite care
u. Therapeutic and supportive counselling service

Acute non-emergency medical care is usually arranged by the family and/or youth with the family physician: the family/patient assumes responsibility for obtaining this care.

Services "b" through "j" are health services which are usually coordinated and supplied on a short term basis by Home Care Programs. When the child needs any of these services on a long term basis, or when the services in categories "k" through "u" are needed, the availability and coordination of these services is not as clear cut.

In areas where some of these services are not readily available, creative solutions by health care, education and social service workers are needed to provide support in the home. This can be provided only by close cooperation and coordination of scarce resources. This requires flexibility in role activities beyond traditional professional boundaries.

8.2 Age-Appropriate Support Services in the Community

As well as providing support services to the child in the home, support services in the community are often needed by children with chronic health problems. Whether these are available in the immediate community or if some travel is necessary depends on the size and geographic location of the community. (See the following Table III)

TABLE III OTHER HEALTH AND RELATED SERVICES

Community support services also include those listed in Table II p. 22. The following services are listed alphabetically and not in order of importance.

a. Audiology

b. Dental care

c. Family counselling and support

d. Grief counselling

e. Health counselling including family planning and human sexuality.

f. Specialty medical care

g. Mental health care

h. Optometry

i. Palliative care

j. Respite care (short term stay)

These services should be supported both by professionals and by the community for a better network system, such as:

- equipment maintenance;
- community volunteers;
- consumer support group;
- information and referral systems

Many of the universally provided community services may need to be modified so that children with special needs can use the same services their friends do. For example access to:

- public libraries/municipal buildings;
- educational opportunities;
- recreational opportunities - including summer camp programs, and year round local community programming;
- transportation.

8.3 Regional Support Services

Highly specialized services with the availability of consultation services should be accessible at least on a regional basis. These services include:

- specialized communication equipment (augmentative devices) and other high technology;
- orthotics;
- prosthetics;
- rehabilitation engineering;
- vocational rehabilitation services.

8.4 Special Community Programs

Special programs in the community provide some of the services for the child with special needs and should also parallel the normal child's social and educational services. These programs should be able to provide access to the community support system for the child.

a. Pre-School Day Nursery - provides an individual program to enhance the child's social, cognitive and physical development. It can be a program component within an existing pre-school program, it can be separate or a program in a children's centre.

b. Special Education teachers for those who need special education classrooms and programs should have access to consultation from health team professionals.

c. Treatment Centres for Children provide a therapeutic program of multi-disciplinary services including assessment and treatment for those with developmental disabilities.

   The service provided to the community should include access to partial hospitalization either during the day time or evening, depending on the child's needs.

d. Team Outreach services for assessment, treatment and consultation should be available for those who do not have reasonable access to community support services. These may be provided by a Treatment Centre for Children or a Community Team specifically developed by a health care facility, specializing in children's needs.

8.5 Total Residential Care [5]

The child or youth who lives in an institution needs all of the services available in the home and community except the home maker. The range of settings should include an apartment with attendant care for adolescents capable of partial or total self-care in activities of daily living.

Examples of long term care settings are:

- residential schools;
- long term care in chronic hospitals, nursing homes and other specialized health facilities;
- acute care hospitals (any hospital caring for child for more than one month);
- hostels;
- youth detention centres;
- supported independent living homes.

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5 See also section VI pages 57 to 90

III SPECIAL ISSUES

There are many special issues which need to be addressed in providing long term care to children and youth. These issues will vary from one facility to another, and each facility should complete its own list and establish a system of reporting and monitoring for each identified issue.

1. DISCIPLINE, RESTRAINT AND TIME-OUT

A philosophy and guidelines for these issues are needed, with staff inservice education, support and direction through established routes to ensure appropriate patient care, e.g., if physical restraint cannot be avoided, there should be mandatory consultation with psychiatry or other available mental health service. Review of the written restraint order is necessary every 24 hours.

Use of "time-out" (isolation) rooms should be avoided. If they are used, policy should include specific guidelines on indications, who can order this, duration of use, staff accompanying the patient in the room, and regular and frequent monitoring of the individual.

2. PARTICULAR NEEDS OF EMOTIONALLY DISTURBED CHILDREN

Emotionally disturbed children need the full spectrum of services and resources that children with other disabilities receive.

Where the child is receiving service for another disability such as mental retardation or physical illness, and where there is, in addition, an emotional disturbance which may be transient or long term, the goal of effective programming is to minimize such disabilities and to detect and deal with them promptly.

Emotionally disturbed children should, to the greatest extent possible, continue to be served within the usual setting. There should be a mechanism for mental health consultation, liaison, and if needed, treatment. This will assist the staff and the service to be most helpful to the child. Staff attitude should be one of positive acceptance and commitment to this child as to their other charges. It is usual for considerable staff inservice and support to be required and for there to be a commitment and flexibility on the part of senior clinical and administrative personnel to ensure that this occurs. The general principles of good service continue to apply.

3. ABUSE AND/OR NEGLECT IN THE INSTITUTION

The overall guidelines must be in keeping with appropriate provincial regulations, with regard to identifying, reporting and responding to abuse and neglect of children in general. It must also be recognized that disabled children and youth are at particular risk.

4. INSTITUTIONALIZATION

Patients and staff in the relative isolation of an institution often become dis-engaged from the community outside. This can be improved by programming, staff rotation and community integration.

5. ISOLATION

There should be frequent monitoring of the need for continued isolation. The adverse psychological and developmental effects of isolation should be combatted. Staff time and material resources should be available to provide needed programs on an individual basis.

6. SEXUALITY

Sexual interest and activity are normal in children and youth. Living away from the family home, and having health problems do not remove this interest, although the difficulty of expressing the interest is compounded. There should be information and dialogue on sexuality with reference to the needs of the particular patient population. Policies should encourage healthy development by enabling contact with peers of both sexes, and by allotting privacy in keeping with the developmental level of the individual.

7. FINANCIAL IMPLICATIONS

Loss or interruptions of income may be especially hard on families with a child with long term illness. There should be mechanisms for obtaining needed financial assistance. Independent agencies, voluntary associations, provincial governments and service clubs often give assistance to families in need of help and should be identified in the community.

8. NON-COMPLIANCE

Non-compliance with treatment, either by the identified patient or by family or caregivers should be treated as a therapeutic problem. It should not be considered grounds for excluding patients from a program except in unusual circumstances.

9. CULTURAL FACTORS

There should be mechanisms for responding to family or cultural practices, behaviours, or issues which need to be considered in patient treatment. Programs serving particular cultural groups should provide appropriate staff orientation and inservice education. Mechanisms should include consulting and cooperating with appropriate external resources, or by including routine cultural consultation for specific religious, cultural and ethnic groups.

10. PATIENT SELF-IMAGE CHANGE

A change in self-image is common in people with health problems. Resources and programs are needed to deal with this.

11. LEGAL ISSUES

Dealing with legal problems of patients in long term care, including legal issues between patients and staff, patients and families, and custody and guardianship, will be influenced by provincial legislation, and lines of responsibility but should include access to legal advice for patients, families and staff.

12. ALCOHOL/DRUG USE AND ABUSE

These problems should be dealt with by established policy, taking into account the patient's developmental level. Education and information programs on substance abuse and liaison with related programs are needed.

13. ADMISSION FLEXIBILITY

Admission policies should include short term and respite admissions in order to support those living in the community. A formal arrangement should exist to ensure that such resources can be efficiently provided on a community or regional basis.

14. HUMAN SUBJECT RESEARCH

Appropriate research policies which include screening of projects by competent, disinterested researchers, as well as by staff, are needed. Where human subject research is contemplated, informed voluntary consent by all patients and guardians is mandatory. Ethical guidelines governing the type of research are mandatory.

15. INFORMED CONSENT

For any experience beyond life-threatening situations there must be informed consent of the child or youth and/or guardian who should know and understand what will be done or will happen and be clearly informed of their option to participate or not. This includes participation in treatment, education and research.

16. QUALITY ASSURANCE

Quality assurance by external audit and other processes are important in ensuring good care and helping in program development. Mechanisms are needed to ensure that these occur continuously.

17. PRIVACY

Living and growing up in a non-family setting for prolonged periods often results in individual needs becoming secondary to institutional practice. Having personal property at hand limits the adverse effects of this. Ready access to a quiet, private space is important. Respect for the privacy and dignity of the individual is essential.

18. ETHICAL ISSUES

It is necessary to identify, consider and decide in advance on how to deal with such ethical issues as research, life support systems, no-resuscitation policy. Policies should be developed on how these situations should be handled. These policies should be acceptable to the community.

19. CHILD AND YOUTH EMPOWERMENT

Young people spending long periods in long term care settings may become passive and accustomed to having all decisions and planning done for them, including daily personal routine. Youth input into their own programs is important and administrative policy should foster this.

IV FAMILY* SUPPORT AND PARTICIPATION IN CARE

The role of the family in supporting the child must not be separated from the highly skilled care being offered by health care professionals and institutions. For a child to achieve independence, self-responsibility and self-esteem, the application of many disciplines properly coordinated is essential. Efforts to attend to the present and future well-being of the affected family members should be viewed as equally important and legitimate components of care.

There is a need for greater recognition of the social contribution of parents and families caring for the sick or disabled. A broad and humane family-centered approach legitimizes meeting family members' needs. The child's physician should facilitate a referral for a parent in need of medical attention. The parent may also need help in obtaining leave of absence from his/her job in order to accompany or care for a child during illness. A letter to the employer advising of the child's illness is often required. A stressed and preoccupied parent may need to be excused from dangerous work.

The initial diagnosis of a chronic health problem often occurs in the acute care hospital. For many parents, this setting may not be conducive to getting adequate rest, nutrition and emotional support; furthermore, parents may be too preoccupied to utilize available resources. Nurses, child life workers, social workers and doctors should be prepared to attend to these needs. In fact, everyone coming in contact with these families, including the clerical and maintenance personnel, should be sensitive to the parents' need for understanding and support.

*Includes the family, as defined in the glossary, guardians and foster parents.

Parents may be especially vulnerable at critical times - on learning their child's diagnosis, awaiting surgery or preparing to go home. For many people, physical and psychological stresses may only surface once the child is home.

While the requirements of the child who is growing and developing differently from the norm can be identified and assessed, the physical and emotional stress on the family and the impact of this stress on the child and on family life must be recognized. Home care and other follow-up programs can help monitor family well-being during lengthy periods of ongoing treatment, with their associated school problems, behavioural difficulties and fear of relapse or complications.

Identifying the resources and requirements of the family and its ability to provide long term care calls for a properly coordinated approach. Because the child's emotional development is so dependent upon the emotional health of the family, this should be evaluated at the outset and continue to be monitored. To understand the changing emotional needs of a family requires reassessment of family resources for the "long haul" when the child is in the home and not subject to the intense scrutiny that is part of institutional care.

The capacity of close relatives to support the family in carrying out its duties should be assessed. At the same time, the needs of other siblings should be considered since concentrating interest and effort upon one child can adversely affect the emotional and social development of other children. Planning for the care and upbringing of the disabled child should acknowledge the need for appropriate relationships between the child and his/her peers as well as with brothers and sisters and other close relatives.

The family needs to be well informed about the child's medical condition.

The nature of the disease or disability, together with the evolving status of the family, will affect the support which the family is capable of giving. The following should be considered and communicated in a timely and continuing manner:

- the nature and expected course of the disease or disability;

- the medication, treatment or appliances required;

- the educational needs of the child;

- the desired recreational and social activities.

Technical Participation - Where circumstances permit, a family should participate directly in the child's health care and treatment. In determining the family's role, consideration must be given to:

- complexity and frequency of the procedure or treatment;

- medical risk involved and the likelihood of error;

- training required to carry out the procedure or treatment;

- cost of treatments or appliances;

- non-medical benefits of such treatments or appliances, including enhanced mobility or comprehension;

- relationship of such treatments or appliances to other patient and family needs;

- whether such treatments or appliances are essential or merely desirable, and whether alternatives are available;

- participation in recreational and social activities;

- enjoyment of a better quality of life;

- limits of family participation.

Financial Impact - The most measurable effect of long-term illness upon a family is the financial one. It is essential to analyze accurately the income available to support the cost being borne by the family by taking into consideration the costs of:

- medication, treatment or appliances;

- transportation and travel;

- medical services not covered by medicare or other insurance programs;

- extended care in a hospital or other institution;

- special education;

- recreational facilities and programs;

- special diets, clothes, toys;

- special services in the home;

- modifications to home, car, beds, bathroom fixtures, telephones, etc.;

- possible relocation or change of job;

Social needs - These differ widely for each individual but the degree to which self-help and integration into the community can be achieved will aid the family in providing support for the child and, at the same time, reflect upon the independence, self-responsibility and self-esteem of both the family and the child. When identifying the social options available to the family, consideration should be given to the following:

- community health, nursing and medical support services available in the community;

- the place of the family in the community;

- the institutions such as schools and churches available in the community;

- the social infrastructure of the community;

- the support of immediate family and friends;

- the opportunities for the child to participate in community life;

- the opportunities for the child to develop and assume responsibility for self.

Organizational Services - Since there are many organizations performing a variety of services the family's needs must be identified so as to determine which organization can be of assistance by consideration of the following:

- the identification of which organizations deal with similar problems or people;

- the cost of these services;

- the accessibility and availability of such services, both geographically and over time;

- the degree to which the organization places demands upon the child and/or the family;

- the impact and relationship of the services offered by the organization upon other services received or benefits delivered to the child or the family; and

- the relationship between the organization and other services offered in the community.

Death of a Child - In the event of anticipated death of a child, parents might need help in planning for the difficult decisions involved.

The turmoil parents experience when confronting the loss of their child's life or the diminished capability for leading a normal life can increase their vulnerability to a wide variety of problems. Their own health, job security and relationships might be at stake.

Professionals and people close to the family should appreciate the family's need and right to experience and express its feelings. Hospital staff, extended family, and friends, in their own discomfort might avoid the bereaved family thus depriving it of needed support. Hospital chaplains can be a helpful resource, particularly for the family far from its usual community religious leader.

Following the death of a child after illness or disability that may have lasted for many years, parents might look to the hospital for special support, particularly from those who had become an intimate part of their family experience. Hospitals should respond to this need while facilitating links to community resources such as groups for bereaved parents. Health care professionals should be aware of existing resources and plan ahead for terminating the relationship. Parents who have had the same experience are often able to provide the most meaningful support. Hospitals should be receptive to these groups and facilitate their functioning, for example, providing space for their meetings. This can help to give legitimacy to the group and prevent continuing dependency on the hospital system.

Siblings of a child who has a life-threatening illness or who has died also need support. Child life and social workers have reported on the positive outcomes of group discussions for school age children and adolescents. Community school teachers can also provide support, when they are informed, equipped, and willing to help.

Summary - Each member of a family can be profoundly touched by the plight of a child with a chronic medical or developmental problem. The

family is thus an appropriate focus for intervention and care by professional and community resources. It is essential that all "helpers" recognize the unique strengths, contributions and vulnerabilities of family members and support family as well as child development at all times.

V EDUCATION, LIFE SKILLS, RECREATION AND CHILD LIFE

PREAMBLE

Much of what healthy, able-bodied infants, children and adolescents learn occurs naturally or almost "invisibly", that is, without planning by others. Their own combined abilities to receive stimuli through all their senses, and to expose themselves independently and energetically to various situations help to guarantee the rich variety of experiences that foster increasingly mature and socially acceptable responses.

Children with less control over their own bodies, minds or environments are at an obvious disadvantage and more dependent on adults for what they experience. However, the adult's very biased perspective about what constitutes important experiences is perhaps the next greatest impediment to learning and development. Certain everyday family life activities may appear to be too routine or ordinary to merit much attention. And the child's or youth's own discoveries or choice of activities may be undervalued for their potential learning impact, and thus are not made possible for those with special needs. For instance the adolescent's apparent aimless and exaggerated amount of 'hanging around' with friends is not often perceived as a means of honing complex and subtle social skills, being exposed to other ideas and values and subsequently furthering self-identity.

Education takes place at all times and in all environments, most of it occurs outside the official education system. The existence and quality of programs to help ensure adequate formal education are erratic. The recognized low level of involvement and meaningful participation by disabled young adults in the Canadian labour market and public life supports the view that there is much room for improvement to our existing approaches.

In addition to the need for improved opportunities and services, there is a need for more relevant education of the various 'providers'. First and foremost among these are the child's parents or other principal caregivers, both in and beyond the home. Because of the influential roles they play, teachers, various health care professionals, day care staff, health care administrators and recreation leaders should all have courses and/or training designed to meet the needs of children with illness or disability. Media personnel and legislators are among those in the community who should be informed about unmet needs and goals of this population.

1. PARENT EDUCATION

No one has a greater influence on the child's education than the parents. This influence should be expressed at two levels: direct care and education of the child; and advocacy to obtain access to other resources. Parents of children with diseases or disabilities must be well-equipped to perform both these important functions. They need to be fully informed of their children's rights and special needs. They need to appreciate the significance of their own role. They need to know specifically what they can do for and on behalf of their child. This information must be conveyed in terms they can understand. Finally, they need adequate emotional support and guidance. The parent who is depressed and apathetic or is experiencing stress from any cause, such as family break-up, should be offered particular assistance in order to be as effective as possible in both the educator and the advocacy roles.

An informed, motivated and supported parent will be more likely to seek out and insist upon receiving educational and other opportunities identified as important. And yet, systematic and comprehensive parent education programs are few and it is still too common for the parent to feel alienated by judgmental professionals who fail to appreciate the

parents' strengths or the complexity of the additional burdens. It cannot be assumed that each family will be given the most appropriate or helpful guidance from the particular professionals with whom there is contact, whether in the health care or in the educational system.

The health care, education and social service systems should establish an appropriate means of assuring that each family is given the opportunity to learn as much as possible about the specific risks and needs of its ill or handicapped child.

Parents should also be informed about how these systems work, so they can seek appropriate solutions to difficulties encountered.

Other valuable educational resources should supplement the more individualized guidance offered by the professionals involved. These include:

- printed guidelines, books or journals;

- organized parent support and education groups, and

- disease or disability-related associations.

When such resources do not exist, parents are often motivated to develop them on their own, or with the help of professionals skilled in this area.

2. INFANT/PARENT DEVELOPMENT AND EARLY CHILDHOOD INTERVENTION

The child's experiences during the first few years of life are commonly viewed by child development experts as having a lasting and fundamental impact on all subsequent development and behaviour.

Good intervention programs provided early enough are sound investments for the child, the family and society.

In Canada, services for children below compulsory school age are characteristically provided by two or more ministries. Lack of coordination, gaps in services, and conflicts over responsibility are frequent and are often at the root of inadequate development of programs. Provincial governments should clarify the mandates of the various ministries for early childhood intervention programs which require the contribution of experts in the fields of education, health and social services. These mandates should stress accountability and coordination.

Special efforts are required and must be legitimized to adapt programs to the needs of families who live far from the centres of expertise. These adaptations might include travelling clinics, transportation and accommodation assistance and regularly scheduled telephone contact for continuing evaluation and guidance.

During infancy, sustained nurturing relationships and appropriate sensory experiences are of paramount importance in achieving developmental potential.

Steps should be taken to ensure that infants have close and continuous contact with and nurturing by the parents. Where this is not possible someone prepared to develop an emotional tie with the infant should be designated as the principal caregiver.

The environment should be planned to give the child the level of sensory stimulation that he/she requires e.g. touch, hearing and face-to-face human interaction. This includes keeping normal day and night hours.

A good infant development program generally is rewarding and stimulating for the parent, whose involvement and sensitive responses to the infant's subtle cues are vital in fostering optimal development. Child development experts are paying increasing attention to the influence of the child in educating and motivating the parent.

Programs designed to foster development in infants and pre-school children are most successful when the family is involved.

3. SCHOOL

Educational services for special needs children and youth are, by definition, intended for the student who cannot benefit from the regular program or who needs additional service prior to coping with regular instruction. Special Educational Services are seen as being separate from those services provided by the regular classroom teacher.

All special needs children, regardless of location or conditions, should receive educational services commensurate with their needs and potential -- and preferably within their own communities.

As far as possible and consistent with their educational needs, children and youth should be maintained in their regular school programs and provided with supplementary instruction or special services as required; however, where special classes are needed, proper personnel, programs and facilities should be provided.

3.1 Assessment

Traditionally, diagnosis has been based upon a model of disability focusing on the etiology and prognosis of atypical conditions. Educational diagnosis and prescription have been practically non-existent. Furthermore, when new techniques and strategies to meet the educational needs of special needs children are developed, there is all too frequently a breakdown in delivery. Therefore, the position would be to emphasize educational-behavioral models in which diagnosis is carried out in order to prescribe necessary education and remediation. This model should facilitate appropriate education.

School board authorities should be responsible for:

- recognizing and assessing learning differences;

- developing techniques to enable special needs children to learn to their greatest potential, and

- providing teams that evaluate, diagnose and identify the special needs child and youth.

Since most professionals agree that early identification of special needs and treatment plans are imperative, systems of identification, screening, placement and continuous evaluation should be started early by educators and others working with community health agencies.

The rights of children and parents should be protected when a child is placed in a program different from those provided for normal children by including the following:

- evaluation consistent with the child's culture;

- evaluation conducted in the child's primary language;

- parental right to obtain an independent evaluation;

- parental consent to placement;

- access to school records, and

- right of parents to withdraw or decline special education services.

3.2 Service Continuum

Special education for children and youth should be a continuum where one extreme is minor assistance to a person in an otherwise normal environment and the other is education in a residential environment. The severity of the disability determines movement in one direction or the other.

3.2.1 Consideration must be given to the numbers of special needs students and the type of educational service they require. School districts, counties or divisions may best provide for special needs children by combining, sharing or contracting special educational services.

3.2.2 Local school boards should be responsible for providing services for special needs children who:

- attend local schools;

- are confined to their homes;

- are placed in health care, correctional, or other treatment centres within a school board's jurisdiction, or

- require services available only outside the local school board jurisdiction.

If a child with special needs has to move to another location, the province should assure funding.

3.2.3 The various provinces typically reimburse school boards the amounts by which special education costs exceed the per pupil costs in each school district, and effective legislation would encourage school boards to identify and evaluate educational needs and provide special educational services for:

- school-age children with special needs whose learning problems are amenable to remediation, or whose rate of development may be improved by special educational services, and

- pre-school children whose educational potential will be irreparably diminished without special education.

3.3 Integration

Integration refers to the involvement of special needs children with normal peers within a school setting.

Essential aspects of integration are:

Instructional integration -- the extent to which the disabled child shares in the instructional environment of the regular classroom; his/her needs must be compatible with the learning opportunities provided.

Social integration -- the relationship between the disabled child and "normal" peers in terms of interactive behavior, assimilation and acceptance.

The opportunity for integration to occur depends on the amount of time that the special needs child spends with "normal" peers, the physical plan and common shared spaces of the school.

Educational integration should involve instructional and social integration that benefit both disabled and "normal" children.

Integration of any special needs child into a regular classroom requires that:

- the educational program of "normal" students is not adversely affected, and

- the students in the regular classroom are sensitized to the experience of the special needs student.

3.4 The Teacher

Increasingly, teachers will have children with special needs integrated into their classrooms, so it is essential that courses about special needs be part of teacher education.

School boards should provide a clear description of the duties of personnel involved with special needs children.

Access to appropriate diagnostic and educational information on the student with special needs before enrolment in the classroom is necessary for effective education.

Collaboration and communication among service agencies dealing with special needs children should be encouraged.

3.5 Classroom Resources

Students with special needs, particularly the severely disabled, often require specialized equipment and furniture to enable them to function adequately in an educational setting. Additional personnel are also required, particularly for the severely physically handicapped. Individual students may need assistance in toiletting, ambulation, feeding, and other self-help skills, as well as in more educationally oriented help such as note takers and "readers" for the blind. Support services such as those offered by physiotherapists, speech language pathologists, occupational therapists, psychologists, social workers, and community health nurses also may be needed.

3.6 Structural Modification and Transportation

The structure of many buildings does not permit easy access by disabled people. To make buildings accessible to individuals in wheelchairs, ramps should be built, doorways widened, bathrooms modified, and other modifications made. Different adjustments are needed for the blind and for other handicapped groups.

Disabled students who can attend school should have the right to transportation to and from school at a cost no greater than that charged to regular students who are eligible for busing.

4. VOCATIONAL AND POST-SECONDARY EDUCATION

Employability, economic independence and self fulfillment are important goals for individual and society alike. Having specific marketable knowledge and work skills are essential for young adults with mental or physical disabilities and, at times, less sophisticated social skills.

5. LIFE SKILLS

The disabled child or youth has fewer opportunities to develop all the skills required for the various roles society expects its members to assume.

Inadequate life skills are frequently responsible for lack of success in academic and occupational pursuits, or in establishing relationships.

A partial list of life skills is outlined in Table IV.

Some of the skills are appropriately taught in the child/youth's living environment, others in the day nursery or classroom, and some in specially-designed environments such as apartments or activities of daily living suites.

For those with decreased motor capacities, occupational therapists should be consulted about special aids and types of programs. The early childhood and school curriculum should focus on many of the life skills. In the area of social skills, psychologists and psychiatrists are valuable resources for providing guidance in setting goals for carrying out periodic assessments and helping to correct maladaptive skills.

6. RECREATION AND LEISURE TIME

All children and youth should be exposed to a variety of programs and opportunities to develop an identity and a feeling of self-worth. They should have ample opportunity to take part in a wide

TABLE IV: LIFE SKILLS (a partial list)

physical self care	: hygiene; grooming; eating; dressing.
group life	: sharing necessary chores; sharing food; objects; space; joint creativity; respecting others' needs; managing time.
household management	: cooking; shopping; laundry; cleaning; pet management; child care.
transportation	: public transit; special transportation; driver education.
personal finances	: budgeting; banking procedures; investing; consumer awareness.
community awareness	: community; municipality; regional; provincial; federal levels.
job related information	: opportunities; occupational skills; resumes and presentation of self at interviews; employer expectations.
leisure pursuits	: interest inventory; community resources; commercial resources; continuing education.
health problem or handicap	: knowledge; psychological acceptance; ability to cope with others' reactions, questions.

variety of recreational activities whether in their home communities, residential institutions or hospitals. The emphasis should be on active involvement more than passive experiences. Whereas entertainment of various sorts should be included, opportunities for physical fitness, risk-taking, creative expression, fun, relaxation, travel, exposure to nature, reading and socialization, among other things, should predominate.

Community recreational leaders should actively foster participation of children and youth with special needs by including them in regular activities, scheduling adapted activities and working to make playgrounds and other facilities accessible and appealing.

Residential institutions should attempt to ensure that children and youth have the freedom, time or privacy to engage in individual activities of choice, and avoid the tendency to provide for recreational needs on a large group basis only.

Efforts should be made to ensure that the child confined to hospital for long periods or for repeated admissions has similar opportunities.

7. CHILD LIFE [6]

To help children cope with the stresses of medical care and hospitalization and to help ensure that important aspects of development are not compromised, child life programs should be a regular part of the overall provisions for care.

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6 See also Child and Adolescent Services in General Hospitals, guidelines for Special Services in Hospitals, Health Services Directorate, Department of National Health and Welfare, 1985, pp. 54 to 57.

Defusing anxiety, helping children and youth to cope with emotionally laden events and helping them to be able to cooperate with necessary treatments are among the important outcomes of the programs.

VI RESIDENTIAL CARE

PREAMBLE

The setting for long term care should always be chosen with the child's best interests in mind. While current practice is to maintain the child in the community, and where feasible with the natural family, there is a continuing need to provide intermediate and chronic care in long term care facilities.

The type of care that best suits the child's needs will be ascertained from the assessment process described in pages 15 to 16. Where either short or long-term care in an institutional facility is recommended, the child may be placed in one of the following types of facilities:

- residential school;
- group home;
- long term care facility;
- acute care hospital (any stay over one month);
- mental health facility;
- mental retardation facility;
- psychiatric hospital;
- chronic care hospital.

The following guidelines define the basic requirements for long term institutional care. They provide an administrative structure and will assist in providing an organizational framework for the application of previously stated principles. Each facility will have special needs according to the programs and services that it offers e.g. residential schools may require specialty medical and therapeutic services.

1. PLANNING FOR ADMISSION AND DISCHARGE

The decision to admit a child or youth must take into consideration alternative methods of care such as a home care program, which may be more beneficial to the child and the family and could result in cost savings.

Policies and procedures must be clearly established in writing to cover a system for receiving admission requests (i.e. intake) and also management of the discharge process.

A clear statement must exist within each facility concerning the types of services provided. This must include defining the types of conditions that children/youth exhibit that can realistically be catered to within the facility.

1.1 Admission Assessment [7]

The admission process includes plans for discharge, is contingent upon assessment of need for service, and must be based both on short and long term needs and goals. It should include plans and opportunities for the child, his or her family and significant others to achieve their greatest potential. Ideally, the plan should begin prior to admission. It should be based on:

- observations of the total needs of the child and the family, and

- examination and consideration of all available resources.

Any discharge plan must include assessment of available resources. Plans are continually

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[7] See also Detailed Interdisciplinary Assessment, pages 15 to 16.

re-evaluated and if necessary, changed. The assessment, early in the admission of each child identified and referred for eventual discharge, should include:

- all of the child's relevant needs, desires, capabilities and resources;

- family capabilities and resources to determine whether they can meet the child's probable needs before, and following discharge;

- consideration of previous medical and social history;

- preliminary determination of what community supports and resources will be needed and whether they exist or should be developed;

- timely and comprehensive documentation on the medical record of needs and plan, and

- nature of relationships and potential conflicts and problems which make effective discharge planning difficult.

1.2 Preparing for Admission

Wherever possible and practical, facility staff should visit the child's home or present facility, and gather appropriate information for the pre-admission conference.

Facilities should encourage pre-admission tours of the unit for children and their families.

Books and pamphlets explaining the facility/unit should be provided to parents and child before or at the time of admission. Information in the pamphlet should include:

- what to tell the child about the facility;

- what to bring to the facility;

- visiting policy;

- overnight accommodations available for parents;

- how to make telephone inquiries;

- facility availability and regulations for parking, T.V., telephones, gift shop, smoking policy, food service and support departments;

- home visit policy, and

- recreational facilities.

Children should be psychologically prepared for admission. There are various methods of preparing children of different ages: printed material (brochures), tours, books, dolls and puppets, role-playing equipment and clothing, films, slides and pictures, and one-to-one explanations at the time of the event. The same techniques can be used to "debrief" children following admission.

On arrival at the unit:

- the child and the parent(s) should be welcomed to the unit by a staff member and escorted to his/her room;

- the admission procedure should be explained to the child and the parent(s);

- the staff member assigned to the child's care should know and understand the child's past, present and potential health problems and the child's usual behaviour and coping patterns by observing and interviewing the child and the parent(s); and

- the child and the parent(s) should be oriented to the unit/facility environment, routines and expectations.

Orientation should include the following:

- introduction to roommates;

- meal times;

- visiting policy;

- smoking policy;

- telephone policy (specific telephone(s) should be reserved for children's use);

- physical environment, bathrooms, playroom, family room, kitchen;

- planning with parents for their participation in their child's care, and

- advising parents and children of avenues available to them for expressing concerns.

There must be a current, individualized care plan for residents that includes both the child and the family (see pages 16 to 18).

1.3 Discharge

In addition to normal discharge policies, particular attention should be paid to the following:

- whenever possible, the parents should be notified as far in advance as a date can be determined when the discharge will occur;

- before discharge, the parents must receive, and understand instructions for follow-up care;

- appropriate agencies in the community should be alerted and liaison established;

- when the plan is for the parents to provide care to their child following discharge they must be thoroughly instructed as to the nature of the care

to be provided, and have the opportunity for supervised practice in the facility, over a period of time, to ensure continuity of care;

- the professional responsible for discharge must document the child's condition on discharge, including health status, and absence of injury, and to whom the child/adolescent is discharged, and

- under normal circumstances, a child should not be released to anyone other than the parents or legal guardian. When the parents or guardian wish to arrange for someone else to pick up the child, they must ensure that this person is a responsible individual and should give him/her their written permission.

1.3.1 Discharge into the Community

For the first three months following discharge, an appropriately trained, designated staff member should be available to the family to assess the effectiveness of the community resources available and make additional referrals as required. Also, the professional should be available to provide emotional support and counselling to the family as required in order to maintain a child at home and in the community for as long as possible.

This follow-up care must be carefully planned with community resources/professionals, preferably people known to the family. Liaison with the facility can continue but must not foster dependence on facility/staff. Teaching should be provided in the home when necessary.

2. BED ASSIGNMENT

In order to ensure that each child receives the most appropriate care, bed assignments should be made in consultation with the unit staff and should take into account:

- availability of beds;

- availability of appropriate staff;

- health problems and level of care required;

- age and developmental level of the patient;

- anticipated family involvement in care;

- anticipated length of stay, and

- cultural background.

Since grouping patients by age more appropriately meets social, emotional and developmental needs of children, it is recommended that:

- children have the opportunity to integrate with other age groupings such as is found in a family unit;

- geographic age groups in all units should have access to privacy areas, telephone access, lounge and socialization areas, with such equipment as a TV, stereo, and electronic games;

- youth should be cared for in a special unit or area designed to support their needs. If a separate youth unit is not practical, these residents should nonetheless be grouped together if at all possible, and

- improved diagnosis and treament enable many patients with diseases such as muscular dystrophy and other chronic conditions to survive into adulthood. Special individualized arrangements should be made for older adolescents or young adults within these special populations. It is likely that in the next two decades, their life expectancy will continue to increase. Special arrangements will therefore be required for these young adults to

cover the transition period between specialized services for children and specialized services for adults.

3. PROVISION OF CARE

Management of care should be provided by an inter-disciplinary team which meets regularly to develop goals and plans of action. One team member is designated as case manager and is responsible for the overall development of the plan and ensuring follow-through of the plans of action. The team should be aware that each child/youth needs a special staff person with whom he/she can feel comfortable in discussing successes and problems. Pertinent information needs to be relayed to the team. The team may include members of all the health care disciplines and the child and parents or guardians.

3.1 Care Planning

In addition to the principles outlined for the Individual Care Plan:[8]

- goals and plans of action are identified by each team member at regular meetings, and are revised and updated as necessary;

- planning occurs informally as well as at regular formal team meetings;

- each discipline is responsible for documenting goals and plans of action for its discipline;

- regular recording must appear on the progress notes to document that the plans of action are being followed through, and

- family/guardian participation is essential.

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8 See Individual Care Plan, pages 16 to 18.

3.2 Intervention [9]

Intervention should start at the beginning of the placement, and include:

- appropriately trained professional intervention (e.g. social worker) with the child and family to mobilize their resources, and remove obstacles to their participating in a program of continued care after leaving the facility;

- intervention with the community to mobilize resources, or to organize additional resources if needed;

- continued communication with all involved;

- arranging for continued treatment of psychosocial problems as appropriate, and

- arranging, whenever possible, for a pre-discharge visit to a home which is new to the child/adolescent who is being discharged.

3.3 Recording

Health care records should include data base and integrated progress notes in addition to other required documentation:

- goal-oriented health recording method should be utilized in order to focus recording on the child's goals[10];

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9 See also Case Management, pages 18 to 19.

10 Information on this type of recording can be obtained by writing to: Bloorview Children's Hospital, 25 Buchan Court, Willowdale, Ontario M2J 4S9.

- an integrated goal list should be a part of the health care plan with copies placed on the chart for easy access;

- the care plan should include specifics of the individual care, responsibilities of team members, equipment needs, timetable for curricular and extracurricular activities;

- the plans of action related to the goals should be included on the care plan stating the discipline primarily responsible, date of goal review;

- results or outcomes should be documented and the goals reviewed regularly.

3.4 Parent/Guardian Participation

Family involvement in the care of the child should be encouraged where it is in the best interests of the child/family. It may include some or all of the following:

- orientation of parents/guardians to the unit, its philosophy, staff, policies and regulations;

- unlimited parent and sibling visiting, which provides emotional support;

- parent/guardian rooming-in (as well as separate parent/guardian lounge on each unit);

- continuous informal and formal consultation with the health care team, of which the parents/guardians are recognized members;

- input to the child's care plan;

- participation in direct care (initially supervised) as well as parent/guardian participation in programs designed to support developmental and psychological needs of children and adolescents;

- information given to parents/guardians regarding privileges, rights and responsibilities;

- regular educational and supportive meetings attended by groups of parents, conducted by staff members experienced in leading groups (the agenda for these meetings is preferably determined by the parents);

- identifying community support/resource groups for the parents by the social worker on the child's team;

- encouraging parents/guardians to take children home whenever possible;

- establishing lines of communication to address issues of parent/guardian concerns, to ensure a flow of information and questions;

- encouraging parents/guardians to advocate on behalf of the child's family, and

- notifying family/guardian of transfer of care from one physician to another.

For further information see Section III, Family Support and Participation in Care, pages 35 to 41.

4. ADMINISTRATIVE POLICIES, PROCEDURES AND CONTROL

Every facility should develop policies which are approved by the governing authority and administration. These policies and procedures should support the facility's and agency's philosophy, mission statement, short and long term objectives, and day-to-day activities. Policies are statements which direct decision-making. They provide a framework within which to achieve the purposes and objectives of the facility. Written policies are essential to formalize a prescribed method of action, whereas procedures expand on this standardization by prescribing how to carry out policy statements through a series of steps. These policies and procedures

should be integrated into a manual to consolidate their location, and to maximize their reference value. The facility should ensure that all staff involved in the care of children are familiar with its contents. To ensure the utility of a manual, all the policies and procedures should remain current, thus requiring a mechanism to update the information.

Function

Policy and procedure manuals are important to an organization in that they:

- identify the organizational structure;
- promote clarity, consistency and continuity of performance;
- establish standards against which actual performance can be measured;
- provide key information for orientation and training programs as well as providing a reference document for ongoing job activities;
- prevent repetitive instructions on routine duties;
- maintain all current and pertinent policies and procedures in a single document, and
- serve as a source document for inspection and accreditation by approval agencies.

Content

The contents of the manual should be restricted to:

- information generally applicable to the intended reader group;
- material which is relatively stable and permanent; and
- material of substantial reference value.

Types

There are two distinct types of policy and procedure manuals which reflect the different levels at which policies exist. These are (1) administrative and (2) departmental. Each of these types is described below. Depending on the size of the facility and the scope of its program, these two types may be consolidated in a single manual with a partition to segregate the contents of each or placed in separate manuals.

4.1 The Administrative Manual

An administrative policy and procedure manual contains overall institutional policies and gives directions for the day-to-day activities of the organization as a whole. The primary function of this manual is to guide the thinking and action of managers in order to integrate their collective efforts to achieve the objectives of the institutions.

The following is a list of suggested topics which should be developed and contained in the Administrative Policy and Procedure Manual. These items should be considered examples of the core of important issues with additions being made in accordance with the needs of the organization. (This list is not exhaustive)

- abuse
- administrative on-call arrangement and schedule
- admission policy
- affiliation agreements
- alcohol and non-prescription drug use
- budgeting process
- capital equipment
- complaints
- communicable disease prevention
- consents
- deaths and autopsies
- disaster plan
- discharge and transfer policy
- disclosure of information

- donations and bequests
- fire safety and prevention program
- incident reporting
- infection control
- information and communications
- insurance and liability coverage
- leaves of absence for residents
- medication
- missing residents
- passes
- personnel policies - hours of work, sick leave, vacation, uniforms, etc.
- petty cash
- purchasing policies and procedures
- quality assurance
- record maintenance and disposal
- referral and follow-up
- release of information
- resident council
- residents' education
- residents' personal belongings
- restraints
- safety and accident prevention
- separations policy
- smoking
- transfer of functions - delegated medical acts
- transfers
- translation
- transportation
- trust accounts
- visiting
- volunteers

4.2 Manual governing the operation of the service

This policy and procedure manual governs the operation of one or more services. The manual contains the policies and procedures which indicate the "how to" for that service and directs its day-to-day activities. While the contents of the departmental manual will vary from service to service, each manual should:

- define the purpose and state the goals of the service;

- illustrate the organizational structure of the service demonstrating the authority, responsibility and accountability for individuals;

- describe the relationship of the service to other services within the organization;

- provide detailed instruction for the functions of the service;

- contain the personnel policies specific to the service;

- communicate the role of the service in fire safety and prevention and disaster planning;

- contain the work schedules for the various jobs within the service, and

- include job descriptions for the various job classifications of the service.

5. SPECIAL SERVICES, PROGRAMS AND OPPORTUNITIES

The facility should provide or have ready access to the following services, programs and opportunities:

5.1 Specialized Professional Services

- provided by professionals with expertise in specialized areas.

5.2 Psychosocial Care

- has equal importance with physical care. Needs include dealing with rejection, separation from family, coping with a long term condition (possibly a terminal illness), learning to initiate, maintain and terminate relationships.

5.3 Counselling

- provided by qualified staff specifically trained by the long term care institution, and by outside resource people, to meet the individual needs of the child and family and staff.

5.4 Sexuality Counselling

- provided in a sensitive, factual manner by staff specifically trained to meet the special needs of children and youth in long term care.

5.5 Advocacy Program

- encouragement should be given to identifying an advocate for the child.

  The advocate may be the parent/guardian, friend or interested staff person or volunteer.

5.6 Realistic Independence Skills Program

- taught on a regular basis using the child's abilities and potential to help in coping with the realities of life.

5.7 Cultural Norms

- opportunities for cultural experiences should be respected and encouraged by provision of opportunities to observe religious ceremonies and rituals, and to learn ethnic languages.

5.8 Opportunities for Community Contact

- provided with assistance of volunteers and use of community activities and resources, and appropriate and available transportation.

5.9 Opportunities for Normal Life-Cycle Events and Experiences

- encouraged by provision of age appropriate activities that approximate those available to peers living in the community. The institution has a responsibility to discourage a community attitude which regards the child as a subject for pity and charity and to promote an attitude that encourages opportunities for normalization.

5.10 Self-development Program

- encouraged through training in assertiveness and independence skills as a self advocate. Deals with social skill development, appearance, deportment and promotion of positive self images.

5.11 Leisure time Planning Program [11]

- encouraged by providing recreational activities, opportunities for lessons or appreciation programs tailored to the interests and abilities of the children. For this population, hobbies and interests have a special importance as they can give the children a sense of identity and purpose. This is especially true if their disabilities preclude vocations or formal education.

5.12 Behaviour Management Program

- standards of behaviour are clearly outlined. Children experiencing difficulties in managing their own behaviour are assisted through general logical consequences that apply to all patients, or by the development of behaviour management programs designed by the inter-disciplinary teams with the residents' input.

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[11] See also Section on Child Life, page 50 to 51.

5.13 Education [12]

- There is a need to provide appropriate educational experience for young people both in community schools and in the long term care setting. The essential components of such programs should include:

- staff trained in special education and sensitive to the educational and psychosocial needs of the students;

- programs available at the level of the student's individual ability, including the integration of life skills into the curriculum wherever possible;

- adapted equipment to allow for greater student independence and expression, and

- accessible facilities, including proper ramping, elevators and washroom facilities.

5.14 Specialized Education Programs [13]

- provided in accessible facilities, with adapted equipment and specialized techniques available in an in-house or community setting. Educational programs are designed to meet individual needs.

5.15 Community Consultation Program

- encouraged to promote good rapport and understanding with community agencies. Example: institution supports child in local school by providing liaison and consultation with teachers.

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12 See also Section V pages 43 to 55.

13 See also Section V pages 47 to 55.

5.16 Palliative Care

- provided by understanding staff in a caring manner and environment where the child is helped to approach death in a manner culturally appropriate.

5.17 Pastoral Care

- provided by a chaplain or other individuals who interact on many levels with children in order to develop an understanding of their spiritual needs and to gain their trust.

5.18 Young Adult Program

- special considerations needed for this age group.

5.19 Nutritional Services

Good nutrition is essential for good health. In long term care facilities, providing a well-balanced diet and meeting special dietetic problems are vital. As well as following Canada's Food Guide for overall nutrition, some of the additional requirements include:

- those based on clinical need;

- dietetic counselling;

- attractive meals served to small groups;

- sufficient time for staff to help children who need assistance or need to be fed;

- opportunities for children to give input into meal planning, and

- educational opportunities so children can learn about good nutrition and meal preparation, even for those unable to actually cook for themselves.

6. STAFF ESTABLISHMENT AND COVERAGE, TRAINING AND QUALIFICATIONS

6.1 Medical Staff

Following admission, each child should be under the care of a named physician. Often, this will be the child's family physician, but factors such as Board policy, distance from the physician's office, or the ability of the physician to visit the facility on a regular basis may make the transfer to another physician's care preferable. Where this occurs, the child or youth and the family should be part of the decision-making process.

6.2 Other Staff

Staff/child ratios vary greatly from program to program and also from time to time within programs. The objective of setting minimum standards is to ensure adequate care, supervision and safety for all the children. In order to set minimum standards the following factors must be taken into consideration:

- the level of care needed by the children;
- the experience and skill of the staff;
- administrative realities within the program and settling;
- provincial staffing guidelines and legislation, and
- effective existing patient classification systems.

6.3 Child/Staff Ratios

The setting of minimum staff/child ratios is often necessary for administrative or funding reasons. Since each setting is unique, these standards must be developed, recognizing provincial guidelines, by adapting ratios in other similar settings, for example, those in other provinces or in similar pediatric or rehabilitation settings. It is likely that ratios will vary from program to program within an institution. For example, residential versus out-patient or assessment versus management programs might have different staff/child ratios.

6.4 Staff Factors

A distinction should be made between direct care staff and other staff members. Direct care staff are those who are primarily responsible for day-to-day child care. Direct care staff do not include those in administrative positions or those who provide ancillary services. When a staff member has both administrative and direct care responsibilities, time should be apportioned accordingly. Direct care staff members include part-timers, but exclude volunteers and students.

Staff recruiting, education and working conditions should reflect the need for the most highly skilled, knowledgeable and experienced staff possible. The variety and balance between types of professional groups and level of education, skill and experience should also be carefully considered. This will result in more efficient staff/child ratios. Whatever staffing mix is used, the facility should have staff with emergency capability, including basic life support CPR and airway management.

6.5 Administrative Factors

The objective of administrative planning and policies regarding staff is to maintain a high standard of care. Factors that should be taken into consideration include staff vacations and illness, minimum safety levels, union contracts and provincial legislation. This should result in specific procedures for flexible staffing and back-up coverage.

6.6 Continuing Education

Since staff must aim to provide optimal long-term physical and mental health care while encouraging the potential in each child, they need the opportunity and encouragement to develop to their own full potential. Staff who are themselves growing in knowledge and skill serve as positive role models and are more likely to foster growth in the young people

they serve. Opportunities should therefore be available for continued inservice programs. However, staff must take responsibility to remain current in their disciplines.

6.6.1 Skill Development

Professional staff members of each discipline require regular opportunities to further develop further in their own areas of expertise. Attending to the bio-psychosocial needs of chronically ill children and their families is a complex and demanding responsibility. In order to to able to provide high quality care, staff must continuously develop their knowledge and skills as a way of refuelling their own resources. A hospital wide quality assurance program, including functional audits, can show where further development is needed. Service staff need opportunities to learn more efficient and effective ways of providing their support services. Current and continual professional clinical supervision is important.

6.6.2 Quality of Working Life

The quality of life of children in long term care is directly affected by the attitudes, values, competence and morale of the caregivers. There is a potential for burn-out of staff working in long term care facilities over extended periods of time. Management must pay attention to this and also to the potential for over-involvement of staff with children on a personal basis.

6.6.3 Management Training

Managers in long term care facilities need opportunities to further their knowledge and skills in managing people and resources. This is particularly vital for those in long term care since their effectiveness does a great deal to determine both the quality of care for long term residents and the quality of working life for the staff who provide the care and service.

7. COMMUNITY INTEGRATION

Access to community-based resources and activities is essential for the child and youth to maintain normal contact and a realistic understanding of the world outside the institution. Community resources and activities may include the following:

- public and private transportation;
- local Parks and Recreation programs;
- Scouting and Guiding programs;
- church groups;
- YM/YWCA and similar programs;
- community centres;
- after school programs;
- local shopping and banking;
- local service clubs;
- community library, and
- local police, fire and other emergency measures organizations through their community relations officers.

Concepts that help the community integration process are as follows:

7.1 Child and Youth Participation

Children must participate in the planning and implementing of these services as well as choosing and controlling the direction of their lives.

7.2 Rights, Responsibilities And Opportunities

Children/youth should have access to the range of everyday experiences to which all citizens are entitled. These rights, responsibilities and opportunities are essential for the child to have autonomy, respect and dignity, e.g. rights of integration mean the responsibility for appropriate social behaviour.

7.3 Appropriateness of Situation

Living conditions, routines or way of life should be comparable to other people of a similar age within the community.

7.4 Use of Community Resources

Community resources, services, facilities, opportunities and relationships available to all people should also be physically and socially available to and be utilized by children and youth. Relevant community groups should be encouraged to use the facility for meetings or recreation. Integration is successful if the agency works with the community and provides appropriate support. Shared programs can be effective both in financial support and staff support.

7.5 Positive Images

The importance of portraying people in a positive way requires a sensitivity to how the image of the person can be affected by our use of language. The size of groups when children/youth are together, and whether the patient is associated with other people or images which enhance his/her value are also important.

7.6 Quality of Life for Children/Youth and Family

Services and opportunities should be provided in a way which ensures the experiences are stimulating,

of high quality and relevant to the child/youth's needs, for example, the person should feel glad to be alive and that life can be "fun".

7.7 Peer Group Interaction and Visiting

There should be opportunities for normal socialization, for example having friends visit for parties, meals, and "sleep overs".

7.8 Public Relations

Efforts should be made to establish a positive attitude within the facility. This will encourage acceptance by the community.

8. TRANSPORTATION [14]

There is a need to provide transportation for children/youth requiring long term care. Transportation provides the link with the outside community which enhances the growth, development and self-image of the children.

The use of a public, community-based transportation system should be encouraged whenever possible. However, such facilities may not be available within the community. An alternative system should be provided when necessary.

Often, community service groups may generously donate funds towards buying a special van to supplement the public transportation system.

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14 See also National Standard of Canada, CAN 3-D409-M84, Motor Vehicles for the Transportation of Physically Disabled Persons, Canadian Standards Association, Rexdale, Ontario, April 1984, and the guidelines for Adult Long-Term Institutional Care, Health Services Directorate, Dept. of National Health and Welfare, 1984, pp. 122-127.

9. VOLUNTEERS [15]

The use of trained volunteers and companions for individuals or groups can enrich the lives of these children. Volunteers often provide a continuous connection with the institution by bringing to it part of the outside world. Volunteers may help supplement the activities of staff but in no way can they supplant them.

There should be a written organizational plan to delineate current responsibilities, relationships and formal lines of communication for volunteers and their inter-relationships with all departments/services, as appropriate. It should be reviewed annually, revised as necessary, and be available to personnel and patients.

The volunteer program, in relation to the total program, should be understood by all staff and volunteers. In order to provide an essential link between the residents and the community, there should be careful planning, delineation of activities permitted, and assignment of a staff member to be responsible for the volunteers.

The volunteer organization should be broadly representative of the community being served.

The volunteers should be accepted as an integral part of the multidisciplinary team and participate in innovative planning and review of programs.

A volunteer group must be organized and directed in a manner that will contribute to a close inter-relationship with the overall objectives of the

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15 See also Child and Adolescent Services in Hospitals. Guidelines for Special Services in Hospitals, Health Services Directorate, Dept. of National Health and Welfare, 1982.

facility. While this direction may be given on a voluntary basis, it may also be provided by a full-time or part-time employee.

The volunteer coordinator should perform the following functions:

- assist the staff in determining the need for volunteer services and developing assignments;

- plan and implement recruitment of volunteers;

- coordinate the recruitment, careful selection and training of volunteers and be involved in the referral of volunteers for placement in appropriate units;

- inform staff as to proper, effective and creative use of volunteers;

- work to increase the readiness of staff to utilize volunteers effectively, and

- keep the staff and community informed about volunteer services and activities.

An orientation program should be organized and implemented. A successful program requires continual supervision and formal evaluation. These activities should be such that the volunteer gains satisfaction from the work. The volunteer's contribution must be recognized perhaps in the form of a volunteer recognition event, with presentation of pins for years of service. The facility should ensure adequate insurance coverage for volunteers.[16]

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16 See also Adult Long-Term Institutional Care, Guidelines for Special Services in Hospitals, Health Services Directorate, Department of National Health and Welfare, 1985, pp. 74 and 75.

Volunteers bring to children those additional services that create a warm and friendly atmosphere in the facility.

10. SPACE ALLOCATION, UTILIZATION AND SPECIAL DESIGN FEATURES [17]

Because the residential care facility may be the child's home for some time, special design features must be incorporated into the building to minimize the institutional nature of the environment. The design must provide space for services that will support social and emotional development. The balance between need for privacy in a homelike setting in contrast to the role of the facility is a challenge for planners of future facilities.

Specifically, total residential care facility planning must consider the following:

10.1 Location and Site

The facility should be in the community close to public and commercial services such as schools, libraries, churches, hospitals, recreation centres, transportation and shops. This allows the residents to remain part of the community and learn how to use the community as independently as possible.

10.2 Access to the Facility

Access to the facility should include:

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17 Note: When reviewing the guidelines for space allocation, utilization and special design features, the reader is reminded that, excluding the features which pertain to mobility and self-care for the physically disabled child/adolescent, these guidelines are written for the development of all facilities for children and youth in long term care.

- space for large vehicle loading zone, under a canopy entrance;

- parking for the disabled, on the same grade as the entrance;

- entrance at grade level or a ramp provided;

- automatic door openers;

- external lighting to allow safe use of the functional and recreational outside areas at night;

- wheelchair trails on the grounds, and

- staff and visitor parking.

10.3 Environmental Features

The external environment should have outdoor grassed space with enough paved areas to facilitate movement of wheelchairs, stretchers and beds. It should be graded for ease of movement, i.e. not totally flat but with no steep grades. There should be adequate shade. Age appropriate equipment and supplies such as sand and water, swings, slides and adapted climbing apparatus are required. Some pleasant "relaxing" places should be provided as well as a storage area for toys and equipment. The area should be usable for winter activities.

The internal environment should include features that provide a home-like atmosphere, that is, sexes not segregated on units, and the children should be in small groups that will foster the sense of family. The environment should permit privacy for the residents but at the same time provide space for fulfillment of social and recreational needs.

Special consideration of lighting, use of colour, noise control and elimination of institutional type odours should be made in order to provide a home-like atmosphere. A variety of design features should be used throughout the facility to enhance orientation.

Air conditioning should be used appropriately for the health and comfort of the residents. Windows should be such as to permit opening during moderate weather, and regulation of the humidity in the building during the long winter months is necessary.

The larger facilities should have small groupings such as the pod concept design. The small grouping within the pod will give the child a sense of family, but a number of pods grouped together in a unit will allow for a proper clinical management plan. Each unit should serve 18-22 children.

Children up to age 5 years can be grouped 2, 3 or 4 in a room. Children aged 5-12 should be two in a room. This will ensure that age appropriate activity supervision occurs in the activity area. Young adults should have their own private rooms.

As a general rule, units that do not have single rooms should provide a quiet visiting room for residents' use with family and friends. There should be enough space planned per bed to allow for the proper allocation of group "up space". Space requirements are defined in existing provincial programs and guidelines.[18]

10.4 Individual Room Requirements

- space for wheelchair transfers, non-electric wheelchair storage, personal storage space, desk/work/play area and space for life support and environmental control systems;

- wheelchair accessible washrooms with fixtures at appropriate height, wheelchair accessible shower stalls with optional hand held shower head and lever-type water taps;

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18 Note that the active treatment hospital space design is <u>not</u> adequate for the long term care facility.

- lever-type door handles or electric switching devices;

- windows that are low enough to allow patients to see outside when they are in a sitting position, that face towards activities of interest and that are equipped with safety devices;

- overhead track to assist with lift for transfers onto bed, and

- walls with space for bulletin boards, posters, art work, seasonal decorations etc.

10.5 Unit Requirements

Each unit (18 to 22 children) should have:

- common room space, with age appropriate decor and. If the common room space consists of a room rather than an open area, it should have two entrances that will allow easy access by wheelchair and, where applicable, a bed or stretcher. Dining areas should be arranged in small "family" groupings;

- accessible snack preparation area;

- young adult areas should have accessible laundry facilities with automatic safety door;

- phone areas that afford privacy and/or own phone in private rooms if resident will be responsible for it;

- space for visiting and "quiet time";

- high traffic areas should have tile surface on floor; in rooms and visiting areas, low mat (wheelchair compatible) carpet should be used where possible to provide a home-like atmosphere;

- specialized bathtub area with lifts;

- electric wheelchair storage and charging space. Electric wheelchairs are not collapsible. It is advisable to check with the Fire Marshal's Office for special requirements;

- provision for parents to stay overnight;

- arrangements for observation and supervision that are not obtrusive, and

- furniture should be suitable to the users and must be adjustable.

10.6 Total Facility Requirements

Larger facilities must provide space for the range of services available to the children.

The services may include:

- acute non-emergency medical care;

- nurses' station;

- social services;

- occupational therapy;

- physiotherapy;

- speech language pathology;

- audiology;

- prosthetics;

- psychology;

- school;

- dental care.

In addition, space will be required for:

- individual assessment/interviewing/administration;

- medical treatment;

- group meetings/education sessions;

- discipline specific professional activities.

The design of this type of space should encourage team interaction wherever possible. All equipment for the services should be age appropriate and/or adjustable in height.

All facilities such as large institutions, residential schools and nursing homes should make provision for:

- safe medication storage;

- indoor recreation (gross motor play);

- quiet group interactions;

- arts and crafts (with storage);

- outdoor play;

- toy library, and

- learning and practising life skills.

11. EQUIPMENT

The type of equipment required should be determined by demonstrated clinical needs and staff competency to provide safe, reliable and efficient care. Equipment policy should be approved by the medical advisory committee and the board of trustees.

11.1 Play and Learning Equipment and Materials

An annual budget should be established for the purchase and maintenance of proper equipment, materials and play-things to support a variety of age appropriate activities for children and young adults. The selection of such supplies should be based on their safety features, durability and adaptability.

Generally speaking, the types of equipment should include play items to permit the young child to engage in 'exercise' or practice play, symbolic play and construction. In addition to the many toys for these purposes, objects normally found around the home, in the health care setting and in nature should not be overlooked. Younger and older children alike need equipment for gross motor play, arts and crafts supplies, books and magazine subscriptions.

Availability of play objects and books should be similar to that of most children living in their own homes.

Radios, televisions, tape recorders, computers and video games and various teaching aids are other standard types of equipment generally included.

11.2 Emergency Equipment

There are different categories or levels of emergency equipment available. Each facility should determine which category of care should be provided e.g. management of seizures, airway obstructions and acute allergic reactions should be considered.

Suggestions to consider are:

Long term care facilities for children and youth with special medical needs should have resuscitation equipment and drugs available and assembled on a wheeled emergency cart with appropriate supplies, equipment and drugs as determined by the medical consultant.

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GUIDELINES FOR POLICIES AND PROCEDURES FOR INSTITUTIONAL PROGRAMS

Guidelines for policies and procedures for institutional programs were formulated after a review of provincial, national and international information.

It is hoped that the following outline will serve as a guide for the development of more comprehensive and specific policies in order to ensure the most effective and efficient delivery of patient care in these units.

I. ROLE AND OBJECTIVES

- Philosophy role and objectives of the program
- Type of patients served
  - By diagnosis and/or severity of illness
  - Restriction of service, if any
- Program provided

II. ORGANIZATION OF SERVICE

- Governing Board responsibility
- Relationship to Administrator and Medical Staff
- Program management

(i) Specific responsibilities of staff

- Medical Director
- Other medical staff
- Nursing staff

- Other staff

(ii) Committees

- Membership to be defined by discipline and number
- Terms of reference to be defined
- Provision for consultation with appropriate hospital and medical staff
- Schedules for formal and ad hoc meetings

III. POLICIES FOR OPERATION OF PROGRAM

1. General

- Admission authority (Identification of individual(s) who have authority to admit)
- Admission priorities by:
  - Diagnostic category
  - Clinical condition
  - Routine admission Standing Orders
  - Medical Orders
  - Emergency admission Standing Orders
  - Length of stay by diagnosis
  - Infection control and isolation
  - Patient records, reports and charting
  - Handling of emergency situations including C.P.R.

- Emergency delegation of responsibility to medical, nursing and/or other staff

- Research/Clinical investigation

- Palliative care, determination of death, authorization for autopsies, handling of bodies

- Referral, consultation (mandatory and other transfer, follow-up)

2. **Staff**

- Selection criteria: education, experience, interests

- Criteria for granting medical/clinical privileges

- Medical coverage/Staff coverage of service

- Delineation of student and supervisor roles including responsibility, authority and accountability

- Position descriptions

- Orientation and continuing education

- Performance evaluation

- Volunteers

3. **Patient**

- Patients' rights

- Patient identification

- Family participation

- Confidentiality

- Patient/family education
- Patient valuables, assets and belongings
- Consent for treatment
- Visiting privileges

4. **Safety**

- Safety and accident prevention
- Reporting of accidents and incidents
- Equipment maintenance and safety
- Fire and disaster plan
- Use of restraints

5. **Quality Assurance**

- Practice standards
- Continuing evaluation of effectiveness of service
- Patient status assessment on admission and discharge
- Incident reports
- Patient care review
- Infection control
- Audits: medical and nursing care, concurrent and retrospective
- Peer review
- Morbidity/mortality review
- Employee performance appraisal

- Product and equipment use and evaluation

IV. PROCEDURES

- Elective procedures
- Emergency alert system procedures
- Medical record and statistical procedures
- Policy and procedure manuals

GUIDELINES FOR INSTITUTIONAL PROGRAMS

The following guidelines have been prepared by the federal-provincial Sub-Committee on Institutional Programs Guidelines. These guidelines were requested by the Federal-Provincial Advisory Committee on Institutional and Medical Care Services. Some of the guidelines are updated versions of guidelines previously published by the Sub-Committee.

Addiction Services
Adult Long Term Institutional Care
Adult Psychiatric Services Provided by General Hospitals
Burn Unit
Cardiovascular Services in Hospitals
Child and Adolescent Psychiatric Services Provided by General Hospitals
Child and Adolescent Services in General Hospitals
Child and Youth Long Term Services
Computed Tomography
Day Medicine
Day Surgery Unit
Dental Care Units in Hospitals
Diabetic Day Care Unit
Diagnostic Imaging Services and Systems, An Overview
Diagnostic Ultrasound Facilities in Hospitals
Emergency Services in Hospitals
Geriatric Day Hospitals
Geriatric Unit in a Hospital
Intensive Care Unit
Nuclear Medicine in Hospitals
Palliative Care Services in Hospitals
Patient Hostel Unit
Perinatal Intensive Care Unit
Pre-Hospital Emergency Services
Pulmonary Function Laboratories
Regional Renal Failure Program
Rehabilitation Medicine Unit

Respiratory Technology Service/Unit
Reuse of Disposables: An Information Report
Spinal Cord Injury Unit
Stroke Services